

Appendix A. Search Strings

Key Question 1

Medline

- 1 exp Disabled Persons/
- 2 exp mental disorders diagnosed in childhood/ or developmental disabilities/
- 3 exp child development disorders/
- 4 limit 3 to yr="1990 - 1995"
- 5 exp Homebound Persons/
- 6 exp cognition disorders/
- 7 exp mental retardation/
- 8 intellectual disab\$.mp.
- 9 1 or 2 or 4 or 5 or 6 or 7 or 8
- 10 exp Disability Evaluation/
- 11 exp factor analysis, statistical/
- 12 exp Psychometrics/mt, st [Methods, Standards]
- 13 10 or 11 or 12
- 15 9 and 13
- 16 limit 14 to english language
- 17 limit 16 to yr="1990 -Current"

PsycInfo

1. exp disabilities/ or exp developmental disabilities/ or exp learning disabilities/ or exp multiple disabilities/ or exp reading disabilities/
- 2 exp Homebound/
- 3 elderly.mp.
- 4 disabled person.mp.
- 5 exp Cognitive Impairment/ or cognition disorder.mp.
- 6 1 or 2 or 3 or 4 or 5 177691
- 7 exp Disability Evaluation/ 34094
- 8 exp Factor Analysis/ 17649
- 9 exp Psychometrics/ 46844
- 10 7 or 8 or 9 93277
- 11 6 and 10 4042
- 12 limit 11 to (english language and yr="1990 -Current")

ICF Update Search

Medline

1. International classification of function\$.mp.
2. ICF.mp.
3. 1 or 2
4. limit 3 to (english language and yr="2008 -Current")

PsycInfo

1. international classification of function.mp.
2. icf.mp.
3. 1 or 2
4. limit 3 to yr="2008 -current"
5. limit 4 to english language

Key Question 1b

Medline

The basic search algorithm is presented first, using the diabetes secondary conditions as the condition of interest. For brevity, the basic search algorithm is followed by the specific search terms for the other basic medical service needs and secondary conditions.

- 1 exp Disabled Persons/
- 2 exp mental disorders diagnosed in childhood/ or developmental disabilities.mp.
- 3 exp child development disorders/
- 4 limit 3 to yr="1990 - 1995"
- 5 exp homebound persons/
- 6 exp cognition disorders/
- 7 exp mental retardation/
- 8 intellectual disab\$.mp.
- 9 1 or 2 or 4 or 5 or 6 or 7 or 8
- 10 exp frail elderly/
- 11 9 or 10
- 12 (randomized controlled trial or clinical trial).pt.
- 13 (randomized controlled trials or random allocation or clinical trial or double blind method or single blind method).sh.
- 14 exp clinical trial/
- 15 (clin\$ adj25 trial\$).ti,ab.
- 16 ((singl\$ or doubl\$ or trebl\$ or trip\$) adj25 (blind\$ or mask\$)).ti,ab.
- 17 (research design or placebos).sh.
- 18 (placebo\$ or random\$).ti,ab.
- 19 cohort studies/ or comparative study/ or follow-up studies/ or prospective studies/ or risk factors/ or cohort.mp. or compared.mp. or groups.mp. or multivariate.mp.
- 20 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
- 21 11 and 20
- 22 exp diabetes mellitus/
- 23 (uncontrolled or noncontrolled).mp.
- 24 22 and 23
- 25 21 and 24
- 26 exp diabetes complications/
- 27 exp diabetes mellitus/co
- 28 26 or 27
- 29 21 and 28
- 30 25 or 29
- 31 limit 30 to (english language and yr="1990 -Current")

Pneumonia

- 22 exp Pneumonia, Bacterial/
- 23 exp pneumonia/
- 24 exp bacterial infections/

Asthma

- 22 exp asthma/

Gastroenteritis

- 22 exp gastroenteritis/

Hypertension

- 22 exp hypertension/

Obesity

- 22 exp obesity/

Pressure Ulcers

- 22 exp pressure ulcer/

Preventive Dental

- 22 exp Preventive Dentistry/
- 23 exp dental care/
- 24 exp bacterial infections/

Preventive Health

- 22 exp Preventive Health Services/
- 23 exp Preventive Medicine/

All of the above searches were repeated with frail elderly replaced by elderly and ADL terms:

- 21. exp elderly/
- 22. (ADL or Activities of Daily Living).mp.
- 23. function.mp.
- 24. 21 and 22 and 23

PsychInfo

- 1. exp disabilities/ or exp developmental disabilities/ or exp learning disabilities/ or exp multiple disabilities/ or exp reading disabilities/
- 2. exp Homebound/
- 3. elderly.mp.
- 4. 1 or 2 or 3
- 5. disabled person.mp.
- 6. exp Cognitive Impairment/ or cognition disorder.mp.
- 7. 4 or 5 or 6

8. exp Asthma/
9. 7 and 8
13. limit 9 to "2000 treatment outcome/randomized clinical trial"
14. exp "Activities of Daily Living"/
15. 8 and 14
16. preventive dental.mp.
17. exp Pneumonia/
18. 7 and 17
19. exp Diabetes Insipidus/ or exp Diabetes/ or exp Diabetes Mellitus/
20. 7 and 19
21. limit 20 to "2000 treatment outcome/randomized clinical trial"
22. gastroenteritis.mp.
23. 7 and 22
24. exp Hypertension/ or hypertension.mp.
25. 7 and 24
26. limit 25 to "2000 treatment outcome/randomized clinical trial"
27. exp Obesity/ or obesity.mp.
28. 7 and 27
29. limit 28 to "2000 treatment outcome/randomized clinical trial"
30. pressure ulcer.mp.
31. 7 and 30
32. preventive medical.mp.
33. 7 and 32
34. urinary tract infection.mp.
35. 7 and 34

Key Question 2 and 3

Medline

- 1 exp Disabled Persons/
- 2 exp mental disorders diagnosed in childhood/ or developmental disabilities.mp.
- 3 exp child development disorders/
- 4 limit 3 to yr="1990 - 1995"
- 5 exp homebound persons/
- 6 exp cognition disorders/
- 7 exp mental retardation/
- 8 intellectual disab\$.mp.
- 9 1 or 2 or 4 or 5 or 6 or 7 or 8
- 10 exp frail elderly/
- 11 9 or 10
- 12 exp Disease Management/
- 13 exp Patient Care Planning/
- 14 exp Patient-Centered Care/
- 15 exp primary health care/
- 16 exp progressive patient care/
- 17 exp critical pathways/
- 18 exp "delivery of health care, integrated"/

19 exp health services accessibility/
 20 exp managed care programs/
 21 exp product line management/
 22 exp patient care team/
 23 exp behavior control/
 24 exp counseling/
 25 exp health promotion/
 26 exp patient compliance/
 27 exp after-hours care/
 28 ((coordination or coordinated or Multifactorial or multi-factorial or multicomponent or multi-component or multidisciplinary or multi-disciplinary or interdisciplinary or interdisciplinary or integrated or community-based or organized) and (care or approach or intervention or strategy or strategies or management or managing or center\$ or clinic\$)).ti.
 29 exp "organization and administration"/
 30 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29
 31 11 and 30
 32 limit 31 to (english language and humans)
 33 (randomized controlled trial or clinical trial).pt.
 34 (randomized controlled trials or random allocation or clinical trial or double blind method or single blind method).sh.
 35 exp clinical trial/
 36 (clin\$ adj25 trial\$).ti,ab.
 37 ((singl\$ or doubl\$ or trebl\$ or trip\$) adj25 (blind\$ or mask\$)).ti,ab.
 38 (research design or placebos).sh.
 39 (placebo\$ or random\$).ti,ab.
 40 cohort studies/ or comparative study/ or follow-up studies/ or prospective studies/ or risk factors/ or cohort.mp. or compared.mp. or groups.mp. or multivariate.mp.
 41 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40
 42 31 and 41
 43 limit 42 to english language
 44 limit 43 to yr="2000 -Current"

PsycInfo

1 exp Disease Management/ (2338)
 2 exp Treatment Planning/ (3373)
 3 Patient-Centered Care.mp. (280)
 4 progressive patient care.mp. (1)
 5 critical pathways.mp. (24)
 6 health services accessibility.mp. (2)
 7 product line management.mp. (6)
 8 patient care team.mp. (15)
 9 medical home.mp. (160)
 10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (6148)
 11 coordination of care.mp. (202)
 12 care coordination.mp. (267)

13 11 or 12 (442)
14 10 and 13 (53)
15 exp "Quality of Care"/ (6442)
16 exp "Quality of Services"/ (9682)
17 15 or 16 (9682)
18 13 and 17 (69)
19 10 and 17 (186)
20 14 or 18 or 19 (286)

ERIC

The ERIC database has limited search function. All searches were run and results imported into one bibliography from which duplicates were deleted. Articles were limited to 2000 forward.

"Coordination of care" OR "care coordination" OR "quality gap" OR "disease management" OR "medical home"

"access to health care" AND ("program effectiveness" OR "program evaluation" or "Integrated Services")

"access to health care" or "integrated services" AND quality

"integrated services" AND (Health OR Medical)

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Appendix B. Care Coordination Articles

Appendix Table B1. Care coordination studies

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Both coordination types					
Boult, 2008 ¹ US	RCT both	Multimorbid elderly	Elderly	"Guided Care": family/caregiver education, evidence based guidelines, HER	7 RNs educated in guided care program
Claiborne, 2006 ² US	RCT both	Specific illness	Mix	coordination "across array of health services," education to patients and caregivers, social/psychosocial assistance	
Cooley, 2009 ³ US	Prospective observational both	CSHCN	Children	Varied	
Criscione, 1995 ⁴ US	Retrospective observational both	Specific illness	Mix	NP coordinating care across all inpatient and outpatient needs; also working with family, group home, and agency staff to "assure an integrated approach to health care"	
Dicianno, 2010 ⁵ US	Descriptive both	Specific illness	Mix	Patient advocacy, specialist/generalist, social/medical	Presents description of model of many types of providers coordinating to provide support to people with spina bifida and their families over the entire life course
Esposito, 2007 ⁶ US	Descriptive both	Medicaid+chronic+ immobile	Mix	Medical home	
Fitzgibbon, 2009 ⁷ US	Prospective observational both	CSHCN	Children	Centralized services by health plan care coordinators	Case managers were registered nurses working for the health plan (1.5 FTE)
Fitzgibbon, 2009 ⁸ US	Prospective observational both	CSHCN	Children	"Family support" (answering questions, advising on home management, advocacy for family/patients); "Condition management" (office visits, progress toward care plan goals); referral to specialty care, etc.	Clinics varied in number of interactions per patient and use of phone vs. office visits
Friedman, 2009 ⁹ US	RCT both	Medicare+disabled+ heavy users	Elderly	Nurse case management: disease management, frequently across multiple chronic illnesses	

Appendix Table B1. Care coordination studies (continued)

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Hebert, 2010 ¹⁰ Canada	Prospective observational both	Frail elderly	Elderly	Coordination-type integrated service delivery	Case managers (nurses, social workers, or other health professionals) working closely with PCP
Judge, 2011 ¹¹ US	Before-after both	Specific illness	Elderly	Family/caregiver, social/medical integration, IS to enable coordination among providers	
Marek, 2006 ¹² US	Prospective observational both	Medicaid+eligible for inst	Mix	Nurse care coordination including home care services	
Melis, 2010 ¹³ Netherlands	RCT both	Frail elderly	Elderly	Integrated, interdisciplinary treatment plan and ongoing home visits for evaluation	Geriatric specialist nurse doing home visits; gps and geriatricians
Nishikawa, 2011 ¹⁴ US	Survey both	CSHCN	Children	Preparation for transition from pediatric to adult healthcare	N/A
Oeseburg, 2009 ¹⁵ International	Review both	Chronic disease or frail elderly	Mix	Patient advocacy model (not "interrogative"/gatekeeper)	Varied
Ornstein, 2011 ¹⁶ US	Before-after both	Immobile+transition from inpt	Mix	Transition from inpatient to home	Led by Nurse Practitioner; initial 3 month pilot period during which program was introduced and "iteratively modified"--no data collected during pilot period
Palsbo, 2007 ¹⁷ US	Before-after both	Medicaid+physical disabled	Adults	Holistic focus on care and service needs	
Palsbo, 2010 ¹⁸ US	Retrospective observational both	Medicaid + specific illnesses	Adults		
Raphael, 2009 ¹⁹ US	Survey both	CSHCN	Children	Medical home	Interprets results of the National Survey of Children with Special Health Care Needs
Schuster, 2007 ²⁰ US	Prospective observational both	CSHCN	Children	Nurse or social worker coordinating care, mostly over the phone	
Singh, 2009 ²¹ US	Survey both	CSHCN	Children	Medical home	N/A
Stewart, 2009 ²² Canada	Guideline development both	Physical and developmental disabled children	Children	Transition from pediatric to adult services	Published/unpublished literature; focus groups and interviews with consumers, community members, service providers, and policy makers
Strickland, 2009 ²³ US	Survey both	CSHCN	Children	Medical home	Interprets results of the National Survey of Children with Special Health Care Needs

Appendix Table B1. Care coordination studies (continued)

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Tourigny, 2004 ²⁴ Canada	Prospective observational both	Frail elderly	Elderly	Social/medical, between providers	
Turchi, 2009 ²⁵ US	Survey both	CSHCN	Children	Specialist/generalist, family/caregivers empowerment and self-efficacy, social/medical integration, school/healthcare coordination	N/A
Van Achterberg, 1996 ²⁶ Netherlands	Prospective observational both	Elderly+chronic disease	Elderly	Creating care plan and making sure it is carried out	Professional care coordinators (e.g., community nurse, family physician, social worker) and nonprofessional care coordinators (spouse, child, relative, etc.) who received instruction on care coordination
Wolff, 2010 ²⁷ US	RCT both	Multimorbid elderly	Elderly	"Guided Care": family/caregiver education, evidence based guidelines, HER	7 RNs educated in Guided care program
Wood, 2009 ²⁸ US	Prospective observational both	CSHCN	Children	Practice-based care coordinators vs. agency-based care coordinators	Nurse care coordinators placed onsite in 3 practices along with training and quality improvement on principles of medical home
Wood, 2009 ²⁹ US	Survey both	CSHCN	Children	Title V agency, medical home	Unclear--varied by practice
Eklund, 2009 ³⁰	Review	Frail elderly	Elderly	Varied	
Mastal, 2005 ³¹ US	Expert recommendations based on visits to 7 pilot programs	Medicaid+disabled or chronic	Adults	Varied	Varied
Wise, 2007 ³²	Review	CSHCN	Children	Varied	Varied
Coordination within					
Danzer, 2010 ³³ US	Prospective observational	Specific illness	Children	Specialist/generalist	Pediatrics, surgical, neurodevelopmental specialists
Temkin-Greener, 2008 ³⁴ US	Claims review	Frail elderly	Elderly	Specialist/generalist, acute and chronic care	
Coordination across					
Boisclair-Fahey, 2009 ³⁵ US	Before-after	Specific illness	Children	School/healthcare coordination	Nurse practitioner contacted school nurses

Appendix Table B1. Care coordination studies (continued)

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Claiborne, 2006 ³⁶ US	RCT	Specific illness	Mix	Family/caregiver education, patient education, social services/medical integration	Practice-based social workers
Dise-Lewis, 2009 ³⁷ US	Before-after	Specific illness	Children	Social/educational	Parents and school personnel met with "consultants" 3 times to learn about and discuss the impact of brain injury on the child and how to best help the child learn
Douglas, 2007 ³⁸ US	Randomized trial	Frail elderly	Elderly	Patient/family/caregivers coordination and communication with physicians	Advanced practice nurse
Nolan, 2007 ³⁹ US	Survey to assess family satisfaction with care coordination services	CSHCN + physical disabled	Children	"Family centered care coordination": communication with providers and b/w providers and schools; help getting access to medical equipment, acute care, specialists	Different coordinators for different needs: NP, SW, PT, OT all provide coordination
Wade, 2009 ⁴⁰ US	Before-after	Specific illness	Children	Education for caregivers: parenting skills, stress management, and coping	Web-based learning
Xenakis, 2010 ⁴¹ US	Descriptive/program evaluation	Girls with physical disabilities	Children	Patient empowerment and self-efficacy, social/medical integration	"Expert instructors" program coordinator
Ziviani, 2011 ⁴² Australia	Descriptive	Physical disability	Children	Family/caregiver empowerment, social/medical integration	Study focuses solely on organizational learning strategies: describes implementation of "program logic" sessions conducted with staff from each program; sessions resulted in detailed illustrations of the logical flow of inputs to outputs to outcomes to impacts for the programs being delivered
Ziviani, 2010 ⁴³	Review	Physical disability	Children	Social/medical	10 included studies on early intervention programs for children with physical disabilities

Appendix Table B2. Outcomes used in care coordination studies

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Fitzgibbon,	Children	Both	Use	Process	Number of contacts; number of office visits; activities performed	8 months
Hebert,	Elderly	Both	Function		Functional decline: institutionalization, death, loss of 5 points in SMAF score (Functional Autonomy Measurement System)	4 years
Hebert,	Elderly	Both	Function		Disability and unmet needs: SMAF (functional autonomy measurement system); includes functional ability in ADLs, mobility, communication, mental function, IADL	4 years
Hebert,	Elderly	Both	Function		Disability profile: IsoSMAF profiles--14 profiles generated including motor disability, mental disability, impaired mobility and ADL with cognitive and communicative deficits	4 years
Hebert,	Elderly	Both	Satisfaction		Satisfaction: Health Care Satisfaction Questionnaire--26 statements rated for perception and importance	4 years
Hebert,	Elderly	Both	Self-efficacy		Empowerment: Health Care Empowerment Questionnaire: similar to satisfaction questionnaire	4 years
Hebert,	Elderly	Both	Caregiver		Caregiver's Burden: Zarit Burden Interview	4 years
Hebert,	Elderly	Both	Caregiver		Caregiver's desire to institutionalize: Questionnaire adapted from Morycz Canadian Study on Health and Aging Working Group	4 years
Hebert,	Elderly	Both	Use	Process	Self-reported hospital utilization (ER and hospitalization)	4 years
Nishikawa,	Children	Both	Process		% discussing adult health transition	N/A
Nishikawa,	Children	Both	Process		% discussing adult insurance transition	N/A
Nishikawa,	Children	Both	Process		% "encouraged in self-responsibility for health"	N/A
Oeseburg,	Mix	Both	Use	Process	Hospital admission (6 studies)	10-36 months
Oeseburg,	Mix	Both	Use	Process	Hospital LOS: 5 studies	10-36 months
Oeseburg,	Mix	Both	Use	Process	Emergency department visits: 5 studies	10-24 months
Oeseburg,	Mix	Both	Use	Process	Nursing home admission: 3 studies	12-24 months
Oeseburg,	Mix	Both	Cost		Costs: 3 studies	12-36 months
Ornstein,	Mix	Both	Use		Admissions, 30-day readmissions	Study period (2 years)
Ornstein,	Mix	Both	Cost		LOS, case-mix index, revenue, direct care costs, indirect cost	Study period (2 years)
Ornstein,	Mix	Both	Function	Use	Discharge to home, nursing home, hospice; death	Study period (2 years)
Ornstein,	Mix	Both	Qualitative		Feedback from providers whose patients participated	Study period (2 years)
Palsbo,	Adults	Both	Cost		Median care coordination costs	10-40 months
Palsbo,	Adults	Both	Cost		Mean per member, per month costs	10-40 months
Palsbo,	Adults	Both	Use		ER and hospitalization rates (per member year)	10-40 months
Palsbo,	Adults	Both	Use		Adjusted LOS	10-40 months
Palsbo,	Adults	Both	Cost		Mean cost per hospitalization	10-40 months
Raphael,	Children	Both	Use		Emergency care use: having 1 or more emergency care encounters i the last 12 months	N/A

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Strickland,	Children	Both	Access		Access to medical home, usual source of care, etc.	N/A
Strickland,	Children	Both	Access		Delayed/foregone care	N/A
Strickland,	Children	Both	Access		Unmet health care need	N/A
Strickland,	Children	Both	Function		11+ school days missed because of illness	N/A
Strickland,	Children	Both	Access		Unmet need for family support services	N/A
Turchi,	Children	Both	Caregiver		Family-provider relations including presence of family-centered care	N/A
Turchi,	Children	Both	Caregiver	Cost	OOP expenses, family financial burden	N/A
Turchi,	Children	Both	Caregiver		Hours per week family spends coordinating care	N/A
Turchi,	Children	Both	Caregiver		Impact on parental employment	N/A
Turchi,	Children	Both	Function		School absences	N/A
Turchi,	Children	Both	Use		Frequency of ED visits over previous 12 months	N/A
Wood,	Children	Both	Caregiver	Satisfaction	Parental rating of care coordination services and barriers to care: help with needed services, support from care coordinator, satisfaction with care coordination, barriers to getting health services	18 months
Wood,	Children	Both	Satisfaction	Caregiver	Parental ratings of pediatric services: treatment by office staff, communication with pediatrician, partnering in decision-making	18 months
Wood,	Children	Both	Access	Satisfaction	Connecting to outside resources: parent satisfaction with role played by pediatrician and his/her office staff in making and coordinating referrals	18 months
Wood,	Children	Both	Caregiver		Caregiver burden: limitation of parent's ability to participate in regular activities, financial burden, days of work lost due to caregiver responsibilities	18 months
Wood,	Children	Both	Health		Child health: severity of disease, overall health	18 months
Dicianno,	Mix	Both	N/A		N/A	N/A
Fitzgibbon,	Children	Both	Use		Number of interventions per child	Not specified
Friedman,	Elderly	Both	Satisfaction		Patient satisfaction (patient reported improved health, satisfaction with nurse tool, satisfaction with nurse relationship, satisfaction with PCP, general satisfaction with nurse intervention, improved relationship with family, satisfaction with primary care partnership meeting)	24 months
Friedman,	Elderly	Both	Self-efficacy		General self-efficacy, health self-efficacy, 3 Multidimensional Health Locus of Control subscales	24 months
Friedman,	Elderly	Both	Health	Function	Self-rated health status, SF-36 Physical Component summary and Mental Component Summary; 6 ADL dependence, 6 IADL dependence	24 months
Friedman,	Elderly	Both	Caregiver	Satisfaction	Patient's improved health, satisfaction with nurse tool, satisfaction with nurse relationship, Satisfaction with PCP, general satisfaction with nurse intervention, improved relationship with family, satisfaction with primary care partnership meeting, satisfaction with nurse help to reduce caregiver stress	24 months

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Stewart,	Children	Both	Guideline		Collaborative initiatives are necessary supports for transition	
Stewart,	Children	Both	Guideline		Building capacity of people and communities will enhance transition process	
Stewart,	Children	Both	Guideline		Need for community navigators or facilitators to assist with transition	
Stewart,	Children	Both	Guideline		Information, resources, and services should be accessible and available	
Stewart,	Children	Both	Guideline		Education is a critical component of transition strategy	
Stewart,	Children	Both	Guideline		Ongoing research and evaluation provides the evidence needed for success	
Singh,	Children	Both	Access		Having a medical home	N/A
Singh,	Children	Both	Satisfaction		Effective care coordination	N/A
Singh,	Children	Both	Caregiver		Family centered care	N/A
Singh,	Children	Both	Access		Problems with needed referrals	N/A
Van Achterberg,	Elderly	Both	Health	Function	Number of disorders	12 months
Van Achterberg,	Elderly	Both	Health		Perceived health	12 months
Van Achterberg,	Elderly	Both	Function		ADL and IADL impairments	12 months
Van Achterberg,	Elderly	Both	Process	Use	Types of caregivers, frequency of contacts	12 months
Van Achterberg,	Elderly	Both	Satisfaction		Satisfaction with caregivers	12 months
Van Achterberg,	Elderly	Both	Health	Function	Quality of life (unclear what the measure was)	12 months
Wolff,	Elderly	Both	Caregiver		Caregiver depressive symptoms: CES-D (Center for Epidemiological Studies Depression scale)	18 months
Wolff,	Elderly	Both	Caregiver		Caregiver strain: Modified Caregiver Strain Index (CSI)	18 months
Wolff,	Elderly	Both	Satisfaction		Patient Assessment of Chronic Illness Care (PACIC): includes goal setting, coordination of care, decision support, problem solving, patient activation, aggregate of all of the above	18 months
Wolff,	Elderly	Both	Caregiver		Caregiver productivity loss: Work Productivity and Activity Impairment (WPAI:CG)	18 months
Wood,	Children	Both	Caregiver		Caregiver burden: to what degree caregiving limited parents' ability to participate in regular activities, financial burden from health care costs, days of work lost to caregiver responsibilities	N/A
Wood,	Children	Both	Satisfaction	Caregiver	Parental perception of pediatric services: adapted from Consumer Assessment of Health Plans Study (CAHPS) and Medical Home Family Index (MHFI). Includes treatment by office staff, communication with pediatrician, partnering in decisionmaking, and connecting to outside resources	N/A
Wood,	Children	Both	Access		Domains covered in focus groups: needs, services utilization and access, care management	N/A
Melis,	Elderly	Both	Process		Adherence to recommendations	N/A
Boult,	Elderly	Both	Satisfaction		Patient Assessment of Chronic Illness Care (PACIC): validated measure of pt perception of various qualities of chronic care	6 months

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Boult,	Elderly	Both	Provider	Process	Primary Care Assessment Tool (PCAT): physician assessment of quality of care and processes of care	1 year
Boult,	Elderly	Both	Health	Function	SF-36 PCS and MCS	Only baseline reported
Criscione,	Mix	Both	Use	Cost	Hospital care: LOS, total charges	3 years of data used
Esposito,	Mix	Both	Process	Use	Case manager and provider contacts (count)	
Esposito,	Mix	Both	Use		Hospital admissions and LOS, ER visits, nursing home admissions and LOS	
Esposito,	Mix	Both	Cost		Total costs of care and costs of personal care assistants, prescription drugs, nursing home use, inpatient visits, and durable medical equipment	
Marek,	Mix	Both	Health	Function	Short version of the MDS (Minimum Data Set): 1997 RUGS III Quarterly; used items on ADL, incontinence, cognitive performance, depression, and pressure ulcers	12 months
Marek,	Mix	Both	Health		OASIS: used items on medication management, dyspnea, and pain	12 months
Palsbo,	Adults	Both	Satisfaction		5 items addressing coordination of care (e.g., "someone helped manage health care services")	2 years
Palsbo,	Adults	Both	Satisfaction		Survey derived from CAHPS questions	2 years
Schuster,	Children	Both	Use		Frequency of therapeutic services (speech, occupational, physical)	
Schuster,	Children	Both	Process		Whether therapeutic services were received at school	7 months
Judge,	Elderly	Both	Satisfaction		Survey to assess acceptability and feasibility of program; administered to 6 care coordinators	N/A
Tourigny,	Elderly	Both	Health	Function	Survival without institutionalization	3 years
Tourigny,	Elderly	Both	Function		Desire to be institutionalized (four questions from Canadian Study of Health and Aging OR person has been institutionalized)	3 years
Tourigny,	Elderly	Both	Health	Function	No deterioration at followup (deterioration defined as death, institutionalization, or loss of 5 or more points on SMAF)	3 years
Tourigny,	Elderly	Both	Caregiver		French version of Zarit's Burden Interview	
Tourigny,	Elderly	Both	Use		Administrative data from various sources for medical procedures, drug use, hospitalizations, day surgery, number and type of interventions, long-term care, rehab, day care , or geriatric ambulatory services	3 years
Claiborne,	Mix	Both	Use		Inpatient and outpatient medical use; ER visits	3 months
Cooley,	Children	Both	Use		Emergency department visits, hospitalization rate, ratio of primary care to specialty care (number of visits)	1 year
Danzer,	Children	Med-med	Health		Neurodevelopmental outcome: Bayley Scales of Infant Development	26 months
Temkin-Greener,	Elderly	Med-med	Function		Change in number of ADL's (functional status)	3 years

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Temkin-Greener,	Elderly	Med-med	Use		Service use	Note: this outcome was estimated as a propensity of each site to provide several services
Boisclair-Fahey,	Children	Med-soc	Function		Number of "wet" days per month	6 months
Boisclair-Fahey,	Children	Med-soc	Process		Parent-reported school bathroom survey: questions on access to bathroom, cleanliness, whether child is willing to use the bathroom	6 months
Dise-Lewis,	Children	Med-soc	Process		Acquired Brain Injury Parenting/Teaching Proficiency Scale	Approx 6-7 months
Dise-Lewis,	Children	Med-soc	Function	Behavior	The Neurodevelopmental Inventory: ratings of priority areas from 20 neurodevelopmental clusters (e.g., attention, emotion regulation, motor control, judgment)	Approx 6-7 months
Dise-Lewis,	Children	Med-soc	Function	Behavior	Behavior Rating Inventory of Executive Functions (BRIEF): 86-item behaviorally anchored measure to assess executive functioning in everyday environments	Approx 6-7 months
Dise-Lewis,	Children	Med-soc	Function	Behavior	Behavior Assessment System for Children (BASC): 126-131 item behaviorally anchored inventory designed to assist in differential diagnosis of behavioral and psychological disorders	Approx 6-7 months
Dise-Lewis,	Children	Med-soc	Satisfaction	Goals	Evaluation of program: asked "to what degree the program specifically led to desired positive outcomes" e.g., improved morale, improved family/school working relationship, significantly improved learning on the student	3 months
Wade,	Children	Med-soc	Process	Function	Parent-child interaction: Dyadic Parent-Child Interaction Coding System III (DPICS-III)	Not reported: end of treatment
Wade,	Children	Med-soc	Function	Behavior	Child behavior: Eyberg Child Behavior Inventory (ECBI)	Not reported: end of treatment
Wade,	Children	Med-soc	Satisfaction	Process	Process measures of satisfaction, etc.	Not reported: end of treatment
Ziviani,	Children	Med-soc	Goals		Lists of desired/planned outcomes and impacts of the programs (e.g., "Children are better able to mobilise functionally and comfortably within the community")	N/A
Ziviani,	Children	Med-soc	Process	Caregiver	MPOC: Measure of Processes of Care 56- and 20-item versions-- five subscales enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care for the child and family, respectful and supportive care	
Ziviani,	Children	Med-soc	Satisfaction	Caregiver	CSQ: Client Satisfaction Questionnaire	
Ziviani,	Children	Med-soc	Satisfaction	Caregiver	SSICQ Satisfaction with School-based Intervention and Communication Questionnaire	

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Ziviani,	Children	Med-soc	Goals		Goal Attainment Scale	
Ziviani,	Children	Med-soc	Function		AAPS: Arizona Articulation Proficiency scale--accuracy of speech production	
Ziviani,	Children	Med-soc	Caregiver	Process	Parent survey based on CHOICES (Children's Health Care Options Improved through Collaborative Efforts and Services): provider and family communication and family involvement in decision-making	
Ziviani,	Children	Med-soc	Caregiver	Process	Family Needs Assessment	
Ziviani,	Children	Med-soc	Goals		Individual Educational plans progress toward goals	
Ziviani,	Children	Med-soc	Function		British Ability scales	
Ziviani,	Children	Med-soc	Function	Caregiver	Parent's rating of interactions with preschool peers; structured questionnaire on peer acceptance	
Ziviani,	Children	Med-soc	Function		Griffith's Mental Development Scales	
Xenakis,	Children	Med-soc	Goals	Health	Meeting health goals	3 years?
Xenakis,	Children	Med-soc	Goals	Satisfaction	Effect of program on relationships, independence, goals	3 years?
Claiborne,	Mix	Med-soc	Health	Function	SF-36 physical and mental	3 months
Claiborne,	Mix	Med-soc	Health	Function	Geriatric Depression Scale (GDS)	3 months
Claiborne,	Mix	Med-soc	Process		Adherence assessment: number of instances in which the patient did not follow through with medication regimen, appointments, dietary requirements, etc.	3 months
Claiborne,	Mix	Med-soc	Process	Satisfaction	Service needs assessment: number of nonmedical services needed to improve patient outcomes; satisfaction with those services	3 months?
Douglas,	Elderly	Med-soc	Health	Function	APACHE III (Acute Physiology and Chronic Health Evaluation)	24 hours
Douglas,	Elderly	Med-soc	Health	Function	SF-8	8 weeks
Douglas,	Elderly	Med-soc	Health	Function	OASIS (Outcomes and Assessment Information Set)	8 weeks
Douglas,	Elderly	Med-soc	Cost	Use	Resource use: standardized charges for rehospitalization, long-term acute care, rehab, SNF, home health resources, etc.	8 weeks
Douglas,	Elderly	Med-soc	Health		Survival	8 weeks

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Nolan,	Children	Med-soc	Access		Access to services and referrals (several survey questions)	N/A
Nolan,	Children	Med-soc	Process		Frequency of communication: medical personnel to school, medical personnel to each other, information sharing	N/A
Nolan,	Children	Med-soc	Process	Caregiver	Responsiveness, choices and alternatives, involving caregivers in care decisions	N/A
Nolan,	Children	Med-soc	Process		Ranking issues related to access and care coordination	N/A
Mastal,	Adults	Varied	Health		Incidence of bowel impaction	N/A
Mastal,	Adults	Varied	Health		Incidence of UTI in patients with catheters	N/A
Mastal,	Adults	Varied	Health		Incidence and duration at each stage of pressure ulcers; % detected for the first time at each stage; average length of time to heal; % of participants screened for PU risk; % of patients in high risk with annual Braden score	N/A
Mastal,	Adults	Varied	Process		Management complying with Paralyzed Veterans Association guidelines for autonomic dysreflexia	N/A
Wise,	Children	Varied	Use	Cost	Health care use, health care expenditures	
Wise,	Children	Varied	Process		Use of effective medication, equity of use of effective medication	
Wise,	Children	Varied	Satisfaction		Satisfaction with care	
Wise,	Children	Varied	Health		Asthma status survey	
Wise,	Children	Varied	Access		Access to care	
Eklund,	Elderly	Varied	N/A	N/A	Varied (review)	

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